



# A Strategic Juncture for The National Children's Study

November 29, 2005

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National Institute of Child Health

and Human Development, NIH

Department of Health and Human Services



# PL 106-310: Children's Health Act of 2000

- (a) PURPOSE - ... to authorize NICHD to conduct a national longitudinal study of environmental influences (including physical, chemical, biological, and psychosocial) on children's health and development.
- (b) IN GENERAL - The Director of NICHD shall establish a consortium of representatives from appropriate Federal agencies (including the CDC and EPA) to:
  - (1) plan, develop, and implement a prospective cohort study, from birth to adulthood, to evaluate the effects of both chronic and intermittent exposures on child health and human development; and
  - (2) investigate basic mechanisms of developmental disorders and environmental factors, both risk and protective, that influence health and developmental processes...
- (e) AUTHORIZATION OF APPROPRIATIONS - There are authorized to be appropriated to carry out this section \$18,000,000 for fiscal year 2001, and such sums as may be necessary for each the fiscal years 2002 through 2005.



# NCS Lead Federal Agencies

- Health and Human Services (HHS)
  - National Institutes of Health (NIH)
    - National Institute of Child Health and Human Development (NICHD)
    - National Institute of Environmental Health Sciences (NIEHS)
  - Centers for Disease Control and Prevention
- U.S. Environmental Protection Agency



# Study Concepts

- Aims
  - Identify potential environmental effects: harmful, harmless, helpful
  - For important conditions and diseases of children, identify potential preventable causes
  - National resource for future studies
- Exposure begins with pregnancy and before
- Has power to study high-priority conditions (n~100,000)
- Gene-environment interaction
- Hypothesis driven
- National resource for future studies



# Planning the National Children's Study



- Federally Chartered Advisory Committee
- Twenty-two Working Groups
- Workshops\*
  - Completed - 28
- Pilot studies\*
  - Completed – 10
  - In progress - 12
- Scientific reviews & white papers\*
  - Completed – 12
  - In progress - 4
- More than 2,500 individuals contributed to the scientific development thus far and there is much more to do.

\* <http://www.nationalchildrensstudy.gov/>





# THE NATIONAL CHILDREN'S STUDY

HEALTH GROWTH ENVIRONMENT

## WHAT IS THE NATIONAL CHILDREN'S STUDY?

The National Children's Study will examine the effects of environmental influences on the health and development of more than 100,000 children across the United States, following them from before birth to age 21. The goal of the study is to improve the health and well-being of children.

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## Study News and Related Events

- **NEW!** [National Children's Study Assembly Meeting, November 29-30, 2005](#)
- **NEW!** [National Children's Study E-Update, September 2005](#)

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the research



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## Reviews and Analytic Reports

To inform and develop methods for the Study, various literature reviews, analyses, and "white papers" have been produced. They are continually being added to this section of the Web site.

### Environmental Health Perspectives 2005 Mini-Monographs

[Lessons Learned from the NIEHS/EPA Centers for Children's Environmental Health and Disease Prevention Research for the National Children's Study](#)

[Principles and Practices of Neurodevelopmental Assessment in Children: Lessons Learned from the Centers for Children's Environmental Health and Disease Prevention Research](#)

[Lessons Learned for the Study of Childhood Asthma from the Centers for Children's Environmental Health and Disease Prevention Research](#)

[Methodologic and Logistic Issues in Conducting Longitudinal Birth Cohort Studies: Lessons Learned from the Centers for Children's Environmental Health and Disease Prevention Research](#)

[Lessons Learned for the Assessment of Children's Pesticide Exposure: Critical Sampling and Analytical Issues for Future Studies](#)

[Air Pollution Exposure Assessment for Epidemiologic Studies of Pregnant Women and Children: Lessons Learned from the Centers for Children's Environmental Health and Disease Prevention Research](#)

[Community-Based Participatory Research: Lessons Learned from the Centers for Children's Environmental Health and Disease Prevention Research](#)

[Assessing Social-Emotional Development in Children From a Longitudinal Perspective for the National Children's Study](#)

[Assessing Social-Emotional Development in Children From a Longitudinal Perspective for the National Children's Study: Compendium of Measures](#)

[Final White Paper with Executive Summary: Measurement and Analysis of Exposures to Environmental Pollutants and Biological Agents during the National Children's Study, 11/19/04](#)

[Final Report, Use of 1\) Sensors and 2\) Radio Frequency ID \(RFID\) for the National Children's Study, 08/25/04](#)

*Environmental Health Perspectives (EHP)* is a monthly journal of peer-reviewed research and news on the impact of the environment on human health. *EHP* is published by the National Institute of Environmental Health Sciences and its content is free online. Print issues are available by paid subscription.

**Current Issue** **EHP-In-Press**



Volume 113, Number 11  
November 2005

**EHP-In-Press**

**Past Issues**

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**Important Notice**

**NIEHS considers  
phasing out institute  
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***Environmental Health Perspectives* Volume 113, Number 10, October 2005**

**Mini-Monograph**

**Lessons Learned for the National Children's Study from the National Institute of Environmental Health Sciences/U.S. Environmental Protection Agency Centers for Children's Environmental Health and Disease Prevention Research**

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**Abstract**

This mini-monograph was developed to highlight the experiences of the National Institute of Environmental Health Sciences (NIEHS)/U.S. Environmental Protection Agency (EPA) Centers for Children's Environmental Health and Disease Prevention Research, focusing particularly on several areas of interest for the National Children's Study. These include general methodologic issues for conducting longitudinal birth cohort studies and community-based participatory research and for measuring air pollution exposures, pesticide exposures, asthma, and neurobehavioral toxicity. Rather than a detailed description of the studies in each of the centers, this series of articles is intended to provide information on the practicalities of conducting such intensive studies and the lessons learned. This explication of lessons learned provides an outstanding opportunity for the planners of the National Children's Study to draw on past experiences that provide information on what has and has not worked when studying diverse multiracial and multiethnic groups of children with unique urban and rural exposures. The Children's Centers have addressed and overcome many hurdles in their efforts to understand the link between environmental exposures and health outcomes as well as interactions between exposures and a variety of social and cultural factors. Some of the major lessons learned include the critical importance of long-term studies for assessing the full range of developmental consequences of environmental exposures, recognition of the unique challenges presented at different life stages for both outcome and exposure measurement, and the importance of ethical issues





# Implementing the National Children's Study



- The Study Sample
  - Considerations
    - Six reviews, analyses, white papers
    - Panel of national experts
    - NCS Advisory Committee
  - A probability sample
    - Exposure-outcome relationships apply to all of our children
    - Assures the highest likelihood of not missing important exposures



# National Children's Study Locations

Vanguard locations: Study Centers awarded (bold)

Vanguard locations: Study Centers pending award (*italic*)

**Lincoln, Pipestone, and Yellow Medicine Counties, Minnesota**  
**and Brookings County, South Dakota**

**Salt Lake County**  
Utah

**Waukesha County**  
Wisconsin

**New York City (Queens)**  
New York

**Montgomery County**  
Pennsylvania

**Orange County**  
California

**Duplin County**  
North Carolina

*Orange County*  
Florida

# Implementing the National Children's Study



- Centers to conduct the NCS important for:
  - Expertise and input
  - Capability and facilities
  - Support and ownership
- Center-based implementation of a national probability sample is challenging and unique, requiring:
  - Flexibility and adaptation to the scientific design
  - Creativity
  - Strong, effective coordination



# Sites vs. Centers

- Sites—geographic locations (counties) from which participants will be recruited
  - Selected by stratified probability sample of primary sampling units
  - 105 sites
- Centers—entities or institutions that will carry out study at the sites
  - Selected by a competitive process
  - Each will cover more than one site
  - 30-50 centers



# Today at the National Children's Study



- A very busy and very exciting place
- Transforming the Study Plan into the Study Protocol
- Establishing the infrastructure and machinery to carry out the Study
- Relating to interest in the study at all levels
  - Public and potential participants
  - Communities
  - Local and regional organizations
  - Advocacy groups
  - Scientific community & organizations
  - The Administration and Congress
  - International



# Interest and Responses to the National Children's Study



- Media Placements to Date
  - 138 print placements
  - 206 online placements
  - 184 television placements
  - 29 radio placements
  - **557 total media placements with a total estimated audience of 49,624,799**





# Interest and Responses to the National Children's Study

## Highlighted Media Outlets

- U.S. News and World Report  
(3 articles in the last 3 years)
- Associated Press  
(3 articles in last 2 years)
- Washington Post
- USA Weekend
- Los Angeles Times
- Journal of the American Medical Association
- CNN American Morning
- CNN Headline News
- Health Day
- Science
- Lancet
- Nature
- American Medical News
- Reuters
- United Press International
- Knight Ridder
- New York Daily News
- Newsday
- Philadelphia Inquirer
- Chicago Tribune



# Responses and Comments are Universally Positive and Supportive



Philadelphia Enquirer editorial, Sept. 30, 2005

## **“Needed: Data, patience and funding**

...The picture that emerges should be invaluable in pinpointing the greatest threats to children's health and development, and for setting policy that best supports the nation's 73 million youngsters under 18. ...

The organizers of the study are launching it knowing the government has allocated only a small chunk of the overall cost. There is no way, of course, to guarantee funding 20 years in advance. Here's hoping the data gleaned will be so compelling that the study is fully supported to its end.”



# Interest and responses to the National Children's Study



## Responses in Vanguard Communities

- “This study is an opportunity to assist this nation to answer vital health concerns.” - Joseph DiMino, Director Montgomery County Health Department
- “Research into what causes autism, whether it is genetic or environmental - or a combination of both - will change lives.” - Sarah Christensen, Salt Lake City, mother of autistic child
- “Maybe they [the National Children's Study] can come here and bring attention to the problems (lack of health insurance and dental care).” – Greg Bounds, Medical Center Director, Duplin County
- “This is a wonderful opportunity for the county to participate in a national public health study. It will provide crucial information nationally, and ...valuable insights on local health issues.” – Thomas Hefty, Waukesha County Executive



# Interest and responses to the National Children's Study

## Some of the 49 organizations expressing support for the National Children's Study\*

Ambulatory Pediatric Association  
American Academy of Pediatrics  
American Association on Mental Retardation  
American Chemistry Council  
American College of Obstetricians & Gynecologists  
American Educational Research Association  
American Pediatric Society  
American Psychological Association  
American Society for Pediatric Nephrology  
Association of American Medical Colleges  
Association of Medical School Pediatric Chairs  
Association of University Centers on Disabilities (AUCD)  
Children's Environmental Health Network (CEHN)  
COSSA (Consortium of Social Science Associations)  
Easter Seals  
First Candle/SIDS Alliance  
Genetic Alliance

Jeffrey Modell Foundation  
Learning Disabilities Association of America  
March of Dimes  
National Association of Pediatric Nurse Practitioners (NAPNAP)  
National Black Child Development Institute  
National Center for Learning Disabilities  
National Family Planning and Reproductive Health Association  
National Healthy Mothers, Healthy Babies Coalition  
Population Association of America  
Society for Maternal Fetal Medicine  
Society for Pediatric Research  
Society for Research in Child Development  
Society for the Study of Reproduction  
The Arc of the United States  
The Catholic Health Association of the United States  
United Cerebral Palsy  
United States Conference of Catholic Bishops

\*Statements of support at: <http://nationalchildrensstudy.gov/about/mission/supporters.cfm>



# This National Children's Study Assembly Meeting



- Strategically placed at the intersections of:
  - Planning for the NCS
  - Establishing of the first Centers to begin the Study
  - Preparing for the remaining Centers to carry out the full Study
- Goals of meeting
  - Introduce the first Centers
  - Share scientific developments and progress
  - Address challenges in moving forward



# Challenges for the National Children's Study



- The President's Task Force on Environmental Health and Safety Risks to children, January 2000 – "BE BOLD"
- The national probability sample for Centers to implement is a bold challenge.
- Responses to this challenge were uncertain.
- How has the research community responded to this challenge?







## **Vanguard Center for Duplin County, North Carolina:**

University of North Carolina at Chapel Hill  
with Battelle Memorial Institute and Duke  
University

*Principal Investigator: Barbara Entwisle, PhD*

*Principal Investigator: David Savitz, PhD*

*University of North Carolina at Chapel Hill*



# Vanguard Centers of the National Children's Study



## **Vanguard Center for Orange County, California:**

University of California-Irvine with  
Children's Hospital of Orange County

*Principal Investigator: James Swanson,  
PhD, University of California-Irvine*





## **Vanguard Center for Queens, New York:**

Mount Sinai School of Medicine with  
Columbia University Mailman School of Public  
Health, New York City Department of Health  
and Mental Hygiene, University of Medicine  
and Dentistry of New Jersey, and Columbia  
University Department of Obstetrics and  
Gynecology

*Principal Investigator: Philip Landrigan, MD,  
MSc, Mt. Sinai School of Medicine*





10:00 – 10:30

Break

**ATTEND POSTERS**



# Vanguard Centers of the National Children's Study



## **Vanguard Center for Montgomery County, Pennsylvania:**

Children's Hospital of Philadelphia and  
Drexel University

School of Public Health with University of  
Pennsylvania

*Principal Investigator: Donald F. Schwarz,  
MD, MPH, MBA, Children's Hospital of  
Philadelphia*

*Principal Investigator: Jennifer Culhane,  
PhD, MPH, Drexel University*



# Vanguard Centers of the National Children's Study



## **Vanguard Center for Waukesha County, Wisconsin:**

University of Wisconsin-Madison with Medical College of Wisconsin, National Opinion Research Center, Marquette University, UW Marine and Freshwater Biomedical Sciences Center/Institute for Environmental Health, and Children's Service Society of Wisconsin

*Principal Investigator: Maureen Durkin, PhD, DrPH, University of Wisconsin-Madison*

*Co-Principal Investigator: Chris Cronk, ScD, Medical College of Wisconsin*





# Vanguard Centers of the National Children's Study



## **Vanguard Center for Salt Lake County, Utah:**

University of Utah

*Principal Investigator: Edward B. Clark,  
MD, University of Utah*



# Vanguard Centers of the National Children's Study



**Vanguard Center for Brookings  
County, South Dakota and Lincoln/  
Pipestone/Yellow Medicine Counties,  
Minnesota:**

South Dakota State University

*Principal Investigator: Bonny Specker,  
PhD, South Dakota State University*



# Coordinating Center of the National Children's Study



## **Coordinating Center:**

Westat with University of Pennsylvania,  
Harvard Medical School (Harvard Pilgrim  
Health Care), Daston Communications,  
The Helix Group, The Media Network,  
Syntaxis, Southwest Research Institute,  
Claritas, Inc., and Peters Consulting, Inc.

*Principal Investigator: Carla E. Maffeo,  
PhD, Westat*

